

VU Research Portal

Exploring good care with surveillance technology in residential care for vulnerable people

Niemeijer, A.R.

2015

document version

Publisher's PDF, also known as Version of record

[Link to publication in VU Research Portal](#)

citation for published version (APA)

Niemeijer, A. R. (2015). *Exploring good care with surveillance technology in residential care for vulnerable people*. [PhD-Thesis - Research and graduation internal, Vrije Universiteit Amsterdam].

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.

E-mail address:

vuresearchportal.ub@vu.nl

Chapter 6

Autonomy under surveillance

The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care.

Niemeijer, A.R., Depla, M.F.I.A.,
Frederiks, B.J.M. and Hertogh C.M.P.M.

Published as:

Niemeijer, AR, Depla, MFIA, Frederiks, BJM and Hertogh, CMPM. (2014). The experiences of people with dementia and intellectual disabilities with surveillance technologies in residential care. *Nursing Ethics*. Published online before print June 9 doi: 10.1177/0969733014533237.

ABSTRACT

Background Surveillance technology such as tag and tracking systems and video surveillance could increase the freedom of movement and consequently autonomy of clients in long-term residential care settings, but is also perceived as an intrusion on autonomy including privacy. Objective: To explore how clients in residential care experience surveillance technology in order to assess how surveillance technology might influence autonomy.

Setting Two long-term residential care facilities: a nursing home for people with dementia and a care facility for people with intellectual disabilities.

Methods Ethnographic field study.

Ethical considerations The boards representing clients and relatives/proxies of the clients were informed of the study and gave their written consent. The clients' assent was sought through a special information leaflet. At any time clients and/or proxy were given the option to withdraw from the study. The research protocol was also reviewed by a medical ethics committee.

Findings Our findings show a pattern of two themes: (1) coping with new spaces which entailed clients: wandering around, getting lost, being triggered, and retreating to new spaces and (2) resisting the surveillance technology measure because clients feel stigmatized, missed the company, and do not like being "watched".

Conclusion Client experiences of surveillance technology appear to entail a certain ambivalence. This is in part due to the variety in surveillance technology devices, with each device bringing its own connotations and experiences. But it also lies in the devices' presupposition of an ideal user, which is at odds with the actual user who is inherently vulnerable. Surveillance technology can contribute to the autonomy of clients in long-term care, but only if it is set in a truly person-centered approach.

INTRODUCTION

One of the main perceived benefits of using technology in long-term residential care settings for people with dementia or intellectual disabilities (ID) is that it could increase the freedom of movement and consequently the autonomy of clients. Instead of using certain forms of freedom restriction (such as bed straps or locked doors) in order to manage wandering behavior and/or safeguard clients from (self-inflicted) harm, specifically designed surveillance technologies (STs) can be utilized to increase the client's range of action and movement, albeit in a secure and responsible way (Margot-Cattin and Nygard, 2006; Wigg, 2010; Zwijsen *et al.*, 2012; Te Boekhorst *et al.*, 2013). For instance, tagging and tracking technology, such as electronic bracelets and Global Positioning System (GPS) tags, enables clients to access areas on their own, without any hindrance, but within certain secure parameters. Similarly, ST such as video and audio surveillance and movement sensors might allow the client to move around more freely and at the same time notifying attending staff of any impending danger.

Ethicists have pointed to an inherent ethical conflict in this premise, as monitoring clients using these forms of ST is also perceived as an intrusion on the autonomy (and consequently privacy) of the client (Eltis, 2005; Hughes *et al.*, 2008; Perry *et al.*, 2008). However, the concept of (respecting) autonomy is not very straightforward with regard to the actual living situation of (long-term) care-dependent people, such as people with dementia or ID. In fact, standard views of autonomy emphasizing non-interference and independence have come under more criticism recently and are viewed as having only a limited applicability for long-term care (Agich, 2003; Hertogh, 2005; Bekkema *et al.*, 2013).

There have been few empirical studies that investigated whether and how clients with dementia or ID in residential care benefit from ST. So far, ST has been reported as something which might support well-being (Margot-Cattin and Nygard, 2006) or increase the quality of life (Wigg, 2010). On the other hand, Te Boekhorst *et al.* (2013) concluded that the quality of life of highly dependent nursing home residents with dementia seems to be unrelated to the use of ST versus physical restraints. In addition, Margot-Cattin and Nygard (2006) state that the possible reasons for residents not to benefit from an access system were not particularly investigated in their study and more research is needed as to why people with dementia might not benefit from ST.

Of the three empirical studies to date, all focused on residential care for people with dementia (Margot-Cattin and Nygard, 2006; Wigg, 2010; Te Boekhorst *et al.*, 2013) and none on residential care for people with ID. Despite intrinsic differences between both client groups, the use and application of ST raises very similar (ethical

and legal) issues in people with dementia and ID, specifically within a residential care setting (Welsh *et al.*, 2003; Perry *et al.*, 2008; Niemeijer *et al.*, 2010). In the Netherlands for instance, one judicial framework exists that pertains to the rights of both (institutionalized) groups, specifically with regard to freedom restriction and ST, providing an additional reason to include both people with dementia and people with ID as the focus of empirical research.

Whether the client is benefited by ST, it is necessary to research their perspectives and experiences with ST. Increasingly, ethnography has been recommended as a suitable approach for investigating the experiences of people with dementia or ID in residential care, allowing researchers to obtain ecologically valid insights into client perspectives, not only through verbal communication but also by observing behavior and reactions (Gilbert, 2004; Nygard, 2008). Accordingly, we conducted an ethnographic field study in two different residential care settings whereby the main aim was to explore how clients in residential care experience ST, in order to assess how ST might influence the autonomy of people with dementia or ID.

METHODS

Design

The analysis featured here was drawn from data generated in an ethnographic study conducted between 2010 and 2011 in two residential care settings in The Netherlands. Ethnography is characterized by a prolonged contact with informants and enables the researcher to observe behavior which is best understood in its own natural environment. This explorative study involved participant observation combined with informal conversations with clients, intended both to gain better understanding of clients' experiences with ST and as a clarification of what had just been observed (*member check*), and formal interviews with relevant others, such as family and staff. These were undertaken not only to triangulate and validate the data, but in some cases simply to broaden the view to include the person's immediate context in terms of the social environment (DeWalt and DeWalt, 2010).

Selection of care settings

392 nursing homes and 144 residential care settings for people with ID in the Netherlands were approached through a survey; 160 nursing homes and 79 residential care settings for people with ID returned the survey. Care settings were selected on the following criteria: 1) they shared a multiplicity of ST; 2) ST was used as an alternative to physical restraints, and 3) the application of ST was integral to their care policies (e.g. a specific ST protocol). After having identified more than 30 potential residential care settings, 7 residential care settings expressed a willingness

to cooperate in the research and were visited by the researcher. Ultimately two residential settings were chosen (table 1) where the research took place:

1. A dementia special care unit (DCU) of a nursing home in the North of Holland, consisting of six new small scale units and one large scale unit (43 clients)
2. A residential care facility for people with ID (CFID) in the southwest of Holland providing care for a heterogeneous group of clients with ID, ranging from mild to severe ID. Research was done in six small scale living units: two units for clients aged 45 and above with severe ID (including ID and dementia); two units for clients aged between 18-40 with moderate to severe ID and two semi residential units with clients aged between 25 and 60 with mild ID (42 clients in total).

These two different populations had overlapping features; such as older clients in either settings with dual diagnoses of dementia and ID, and differences, as the average age of clients with ID living in four of the observed six units was lower than that of the DCU. This meant that some of these clients were more mobile and agile and had a tendency to run away (instead of wander off more slowly). With regard to both residential facilities, there were no other obvious differences in activity profile and consequently surveillance needs. However the surveillance of clients with mild ID in the semi residential care units did differ more significantly from those in residential care, as they were deemed capable of doing more themselves (see table 2). In addition the clients with mild ID were easier to communicate with verbally, due to their cognitive abilities.

Informed consent

People with dementia or ID may not always express valid informed consent to participate in research, as they are not always capable of communicating well verbally (Margot-Cattin and Nygard, 2006). In order to protect those individuals taking part in the study, the following steps were undertaken. First, the boards representing clients and relatives/proxies were informed through a letter and granted their written approval. All family or proxies of the clients in the units where the research took place were informed of the research study through information leaflets and were asked to give their written consent. In order to seek the clients' assent, a special information leaflet informing the client of the research study was designed and handed out as well. In addition, every time the researcher participated in a new unit, each client would be informed of his presence and asked by the attending staff whether anyone refused his presence.

Table 1: Characteristics of selected care facilities.

Facility characteristics	Dementia care unit (DCU)	Care facility for people with ID (CFID)
Area	Semi-rural	Urban
Number of units (where the research took place)	7 in total: 6 small scale units + 1 large scale unit (all in 1 location)	6 in total: 4 residential small scale units, 2 semi residential units outside the CFID
Number of clients (who participated in the research)	43 in total (6 clients per small scale unit, 13 clients in the large scale unit)	42 in total (7 clients per unit in the CFID)
Indication ST	by team supervisor and elderly care physician in consultation with family or proxy	by team manager, ID physician and psychologist in consultation with client or family or proxy
Physical restraints	nursing blankets, bedrails, wheelchair table tops and safety belts in the wheelchair, locked doors	nursing blankets, bedrails, safety belts in the (wheel)chair, seclusion area's, locked doors

The researcher was specifically instructed by the management of both facilities to stop gathering data if a client showed any signs of stress or disapproval of the researcher's presence even if there had been no refusal beforehand. At any time both relatives/proxies and client were given the option to withdraw from the study. An information meeting was held for staff prior to the study informing staff of the study and ask for their consent. Finally, formal approval was granted by the management teams of both facilities and the research protocol was reviewed by Medical Ethics Committee of the VU University Medical Center. In order to ensure confidentiality of all informants, all data was anonymized.

Use of ST devices

Table 2 provides an overview of the ST devices which were used in the facilities researched. Most devices were used in both facilities, with the exception of acoustic surveillance and GPS technology, which was only used in the CFID.

Table 2: ST devices and their use in both selected care facilities

Device	Use
DECT phone	Each nurse or support worker was equipped with a DECT phone, enabling them communicate with each other and to 'listen in' on any room of their unit. An alarm on the DECT phone could be triggered by sound and/or movement detection (sensors) which were present in each room. In the DCU the DECT phone was used 24 hours per day, in the CFID only during the day and evening shifts, but not during the night.
Movement sensor(s)	Depending on each individual case, these were switched on or off in the client's bedroom.
Acoustic sensor(s)	In the DCU, depending on each individual case these were switched on or off, in the CFID all the clients were listened in during the night.
Acoustic surveillance	During the night all clients of the CFID were listened in from a central location using the acoustic detection in the clients' room.
Electronic bracelets	In the DCU, 8 clients wore electronic bracelets to which the automatic doors would respond to. The bracelets allowed them to walk within specific areas with set parameters, so called 'living circles'. There were 3 living circles: the small scale living unit, the hallway that led to the units and an extra walking area. Depending on the client, a specific living circle was assigned. In the CFID 4 clients within the facility wore bracelets which only opened to one extra-large corridor, outside the living unit.
Automatic doors	Each door had an access code that only staff and regular visitors knew. However the doors would open to those clients with electronic bracelets.
GPS tags	2 clients in the CFID had a GPS tag, which was sewn into their coats. The GPS tag allowed clients to walk around outside on their own, on the terrain of the CFID. The GPS was linked to the computer in the office part of the living unit.

Video surveillance	In the DCU a camera was used in the hallway connected to a monitor of the night nurses' office. In the CFID a camera was used in a semi residential unit, connected to a monitor in the front office. In addition, individual cameras could be placed and used during the night, monitored from a central location (one client with severe epilepsy had camera surveillance during the night).
--------------------	--

2.5 Data-collection

Data was collected by the first author (A.R.N.) during two different periods: from April 2010 to July 2010 in the DCU and from November 2010 to February 2011 in the CFID. See table 3 for an overview of the characteristics of the data collection. Because participant observation is flexible, it allows for many combinations and permutations of data collection in the research setting (Hoare *et al.*, 2012). For the researcher this meant at times switching from active to moderate participation (DeWalt and DeWalt, 2010) when the opportunity arose. Active participation meant helping out the nurse (assistant) or support worker during a shift- primarily with domestic tasks, such as cleaning, cooking and feeding clients, or accompanying clients on their way to their day activities. Moderate participation meant the researcher would suspend his tasks if and when possible, in order to follow or shadow specific clients who were on the move. All staff was informed beforehand that this could occur during the participation of a shift. Field observations were documented in field notes which included not only observations of all occurrences related to ST, but also reflective comments of the researcher and information from the care plans of the clients to which the researcher was also given temporary access to (i.e. only to be read on location) in both care settings. Next to this the researcher conducted eight formal interviews in the nursing home and five formal interviews in the care facility for people with ID (see table 3), whereby all key informants were purposively sampled. These interviews would last between 45 minutes and an hour and were transcribed ad verbatim. The interview guide used was structured on the field notes and was designed using the same format for all the informants in order to give meaning to the researcher's observations, but also to bring out their perceptions on (how the client experiences) ST, and to elaborate on the meanings they gave to the clients' actions.

Table 3: Data collection

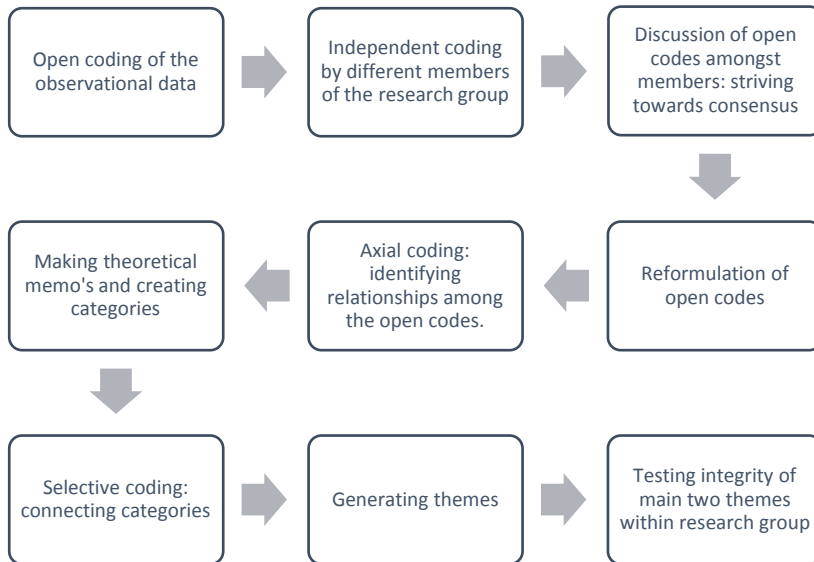
	Dementia care unit (DCU)	Care facility for people with ID (CFID)
Period	April 2010 to July 2010	November 2010 to February 2011
Participant observation in the facilities	14 weeks 3 days a week 200 hours of observation Participating in various shifts; i.e. day, evening and night shifts	12 weeks 2 days a week 140 hours of observation Participating in various shifts; i.e. day, evening and night shifts
Also present at	three rounds with the doctors, two information meetings with family, two 30 minute ST instruction trainings for new staff, during the transfer of shifts and during day time activities with the clients.	a fire safety instruction training for staff, during an exercise session with the clients and physiotherapists, at an ethical committee meeting, during the transfer of shifts and during day time activities with the clients.
Formal interviews	1 member of the board representing clients 2 night nurses 1 nursing assistant 1 elderly care physician 2 team leaders 1 occupational therapist (n=8)	2 two relatives of one of the clients. 1 ID night care manager 1 ID physician 1 cluster manager 1 occupational therapist. (n=6)

2.6 Analysis

A grounded theory approach allows important concepts to emerge out of the data; meaning is created through the generation of data (Corbin and Strauss, 2008). Analyzing in accordance with a grounded theory approach meant data analysis and data collection taking place in the same time frame. This entailed that the data was read preliminary to refine the research question and guide the ensuing data collection and re-read in order to search and identify patterns, after which they were compared and analyzed on differences and similarities ('constant comparison', Glaser and

Strauss, 1967; Corbin and Strauss, 2008). First the field notes and concurrently the interview transcripts were initially coded using open codes and writing initial memos. After identifying core themes related to the research question(s) a focused coding of all the data, together with the second author (M.F.I.D.) was conducted, using integrative memos and linking codes and data to each other in order to identify categories (see figure 1). In order to examine for variance and consistency on these categories, contrasting examples were examined more closely. With the aim of our study in mind, a pattern of themes emerged, which were discussed together with the third and fourth authors (B.J.M.F. and C.M.P.M.H.). The entire process of analysis feedback was given through discussion ('peer debriefing') with other members of our research group and through interim reports on the research findings with an advisory panel of experts from in the field (e.g. physicians, policy advisors and client representatives), with whom preliminary results were discussed. If there were discrepancies in the analysis, these would be resolved through consultation with the panel of experts. During analysis, close attention was paid to the fact that the data reflected several different perspectives (e.g. the formal interview data contained caregiver perspectives, whereas the observational data focused primarily on the clients' actions and views). As it was the clients' experience and behavior that was the primary object of this study, it should be noted that the examples in the results section are all drawn from what was directly observed. As such, the interviews have been primarily used to triangulate the data (and to broaden the view of the client). In the presentation of our findings we try to use 'thick description' (Lincoln and Guba, 1985) by describing the phenomenon observed in sufficient detail.

Figure 1. Process of analysis



RESULTS

How clients in residential care experience ST was understood to create a pattern of the following two themes:

Theme 1. Coping with new spaces which entailed clients: (1) wandering around, (2) getting lost, (3) being triggered, and (4) retreating to new spaces.

Theme 2. Resisting the ST measure because clients (1) feel stigmatized, (2) missed the company, and (3) do not like being 'watched'.

Theme 1: Coping with new spaces

The introduction of ST in both care facilities meant that each client who was still mobile was given a new electronic bracelet, and depending on their activity profile and surveillance needs were allowed to move around more freely in new space, albeit within set parameters. How clients coped with these “new spaces” is illustrated by the different experiences below.

Wandering around

As a result of the electronic bracelets, certain clients in both care settings were constantly on the move in what was now additional space, whereas before these clients had been confined to moving around in their communal living room. Since ST had been introduced, several nurses and support workers had noted that a number of clients had become “less restless” during the night. One of the more “restless clients” (as she was called by staff) in the nursing home, Mrs. V., found it indeed difficult to keep still during the day and even during the evening meal, where she would frequently wander off before the rest had finished, continuously moving around in what was now additional space. Before she would get up she would often proclaim: “I have to go now- otherwise I’ll be late” (field notes, 10 May 2010), often taking some cutlery or other loose items with her, putting them in her handbag and then placing these somewhere else, such as one of the chairs in the hallway, where she would pick them up later again and again place them somewhere else. This would be done repeatedly during the day. The night nurse had noted that Mrs. V. – who, according to her file, had indeed been a frequent night wanderer – got out of bed less since she was able to wander more during the day (interview, 05 July 2010).

Another client, Mrs. T. was not so restless, but with the help of her bracelet, would go for a wander half an hour before lunch every day. The normal routine of all the nurses and nurse assistants was to gather every client at the table at least fifteen minutes before lunch was served, however the nurses made an exception for Mrs. T. and allowed her to go out before lunch because they knew Mrs. T. would return in time.

Getting lost

An increase in freedom of movement with ST could also result in clients being inconvenienced by its use. One such client was Mrs. van D. in the nursing home, who had a tendency to end up in the canteen of the nursing home, sometimes as much as three times a week, where she would often be seen searching for something frantically under and around one of the tables. Frequently she would ask anyone nearby whether they had “seen my two sons?” and whether one could “help me look for them?” On one occasion this ended up in her crying out “I’m lost, I’m lost” (field notes, 24 May 2010), which continued for fifteen minutes after which a nurse, who had been alerted by the kitchen help, came to fetch her.

There were several occasions where clients would end up in the reception area of the nursing home, the neighboring units or the utility room of the residential care facility for people with ID, which in the latter case ended up being locked during the day as a result. The most hazardous situations were those where the client would slip

through doors opened by (often visiting) others and walk out of the bounds of the facility and get lost in the woods or the nearby shopping center, which led the care facility for people with ID to use an additional GPS chip for one of the younger clients named J., so he could be “tracked down” when this happened.

Being triggered

As certain clients are allowed to go beyond a certain set of parameters and see doors opening up (thanks to their bracelets) to new spaces, this often triggered a reaction in other clients who were not allowed to go beyond certain doors, to slip through—ultimately resulting in clients fumbling with a closed door, trying to open it. One of those clients, Mrs. van G. who did not have a bracelet, also tries to slip through the door when she sees another client walking through. After having fumbled with the door audibly for several minutes, without getting it to open, a nurse assistant arrived and sits Mrs. van G. back down on the bench. Mrs. van G. appeared to be agitated, as the following short conversation occurs (field notes, 7 July 2010): “Now I’m sitting here, but that wasn’t the idea! What do you mean by this, Mrs. van G.? I ask. “I didn’t want to sit here...” Because? “Well yes, well. I wanted to go where he went to..! (Mrs. van G. points to the next hallway). At least, that was the idea, but now I am here again” “Again” Mrs. van G.? “Yes ‘again’! They always take things from you that you want to do.”

Retreating to new spaces

One way in which clients negotiated the extra space in both care facilities was to retreat to a separate area other than their own bedroom, thereby carving out a small “extra private space” for themselves. This would often be a particular spot somewhere in the facility to which a client would frequently return to, as was for instance the case with Mr. J. in the nursing home, who would retreat every day to the corner of the hallway which had a large windowsill and a view looking out on the fields. He often used the window sill as his canvas on which he would draw or scribble. The nurses let him do this as long it was with a pencil, and sometimes a nurse would give him a piece of paper. One day, the following short conversation occurs with Mr J., indicating what he appreciated about this corner spot (field notes, 15 June 2010): ‘This is a nice spot Mr. J- and what a view! I say. ‘Yes definitely!’ Mr. J. replies. “It’s nice and quiet here as well.” Quiet? I ask. “Yes you know- the others aren’t here.” One of the nurse assistants stated that she was happy for Mr. J. as before he would retreat to his bedroom and “sit there all day” whereas now he was “out and about more”. Sometimes clients would retreat from their own unit not to be alone, but to visit other, neighboring units. For example, one of the older clients

with ID named R. would visit the living room of his neighboring unit every day and make a particular puzzle at the table there, which he only wanted to do there. After finishing, he would go back to his own unit. One of the support workers explained that they had tried making the puzzle in his own unit, but that he had refused this: he was only content to make it there. The electronic bracelet allowed R. to retreat from his own surroundings and visit another living room.

Theme 2: Resisting the ST measure.

Sometimes clients would resist an ST measure, which according to staff members, was because presumably for them, possible negative consequences of ST outweighed any benefit of increased freedom of movement, as is illustrated by the examples below.

Feeling stigmatized

When the electronic bracelets had been handed out to certain clients in the nursing home, one of the clients, Mr. L, a client with dementia who was very agile and in good physical condition, had been very explicit with regard to wearing an electronic bracelet- having refused it when it was proposed to him by the nursing staff. As Mr. L. did not have a tendency to wander, the staff in alliance with his daughter, decided not to pursue this further for the time being, even though this meant that Mr. L. was primarily confined to the living room. But Mr. L. did not seem to mind and several weeks later, he was still very clear on the topic, conveying one of the reasons why he did not want to wear a bracelet (field notes, 18 May 2010): Having taken Mr. L. outside in the small adjacent garden of his living unit, I ask him once we're seated: What do you make of these electronic bracelets? 'Well it is your freedom of course. The others are constantly stopped'...And wearing a bracelet yourself? 'I just do not like it all.. They'd better not do that with me- then everybody will know you belong to something.. like a patient.'

Missing the company

In the case of H, another client with ID who was given a GPS device to enable him more freedom of movement, there was not an explicit (or verbal) refusal to the device itself. H. rather resisted the fact that the 'joint' activity of walking which required human supervision was changed into an individual 'solo' activity accompanied by electronic supervision. Prior to the GPS device, H., who had difficulty communicating verbally, would go outside every day for a walk together with his support worker. According to his client file H. was raised on a farm and

“enjoys being outside when he can.” However once he was left to walk on his own, H stopped going outside altogether. On the sunniest of days, with the door fully open, H. would be seen sitting inside the living room of his unit showing no intention of moving. When the cluster manager is interviewed 4 weeks later she says the following (interview, 11 January 2011):

‘Yes- we had to reverse this measure eventually, even though we initially reasoned the same with H -as with our other client who has GPS- that it would be better for him...more freedom... We tried practicing, getting him used to walking on his own, but each time he would go back in the house immediately, rain or shine...’

However after the reversal of this measure, H. was seen out and about again during the afternoon with his support worker.

Not wanting to be ‘watched’

The last example shows a resistance by clients against the use of a camera in a semi-residential location. The camera that was placed, was there in order to fend off drug dealers that had come by the residence. One particular client, M, who used drugs, had bought drugs from them in the past, so as a first measure, the door was locked from the inside, curtailing all the clients in their movement. This front door played an important role for those clients who liked to smoke a cigarette, as they would normally do this outside the front door. Because the door was locked the clients had nowhere to smoke, unless a support worker would open the door for them when they wanted to smoke outside. Therefore the location manager thought of the idea of a camera. Prior to installment, all the clients were informed by the two support workers, who told them that it was primarily a safety measure and not to “keep an eye on them” (field notes, 2 December 2010). According to one of the support workers the camera was a temporary measure, until ‘things die down a bit with M and the whole drug thing’ (field notes, 2/12/10). But now every time clients wanted to smoke a cigarette the camera would be hanging there, leading clients to state the following (field notes, 9 December 2010): “that thing has to go away now- I don’t care about the reasons, I want to be able to smoke my cigarette in peace” or: “I can’t be myself around that thing” and (field notes, 10 December 2010): “I don’t like it when there are cameras everywhere, if they hang up anymore then I would ‘sabotage’ them... otherwise you might as well live in prison...!”

The clients indicated that ultimately they would rather have the door closed and have less smoking moments than have the camera present. Eventually it was decided that the camera would be turned off (as indicated by a small red light) by the support worker whenever the clients would smoke outside.

DISCUSSION

Often new care technologies such as ST are welcomed by care providers as they are perceived to be an improvement compared to the previous situation (Welsh *et al.*, 2003), even though there is little empirical evidence on whether and how clients might benefit from this technology.

The aim of this study was to explore how clients in residential care experience ST and how this might influence their autonomy. As the ST used in both settings consisted of such a broad range of devices (see Table 2), a certain distinction can be made with regard to the specific function that ST devices have in conjunction with how the client might experience it. The electronic bracelets allowed clients to wander around in new spaces, thereby providing an opportunity for clients to retreat from the company of others or to search for new company, but this increase in freedom of movement could also lead to clients getting lost and distressed. In addition, by seeing automatic doors opening up to certain clients, this triggers a reaction with other clients who, when halted by a door might get agitated. Clients are also resistant to wearing an electronic bracelet or a GPS tag, as possible negative consequences of ST such as the stigma of wearing a bracelet or the loss of companionship might outweigh any benefit of increased freedom, as was also the case with the use of a camera, which contributed to a feeling of being watched.

How does ST influence the autonomy of the client?

In this study we found that ST might increase the autonomy of the client as it opens up new spaces for clients in which they can choose to wander around in and retreat from others, thereby creating a private space for themselves. However, although there is a vast amount of literature which points to wandering as being necessary and vital to the health of the client (Robinson *et al.*, 2007, Wigg, 2010), it could be argued that for wandering to be beneficial, it should be meaningful to the client. As Smith *et al.* (2009) point out,

‘in too many instances [in nursing homes], people with dementia are left alone, often with nothing to do. The losses that are a part of dementia—such as using language to explain needs or to plan their day—interfere with their engagement in preferred and meaningful activities. Too often, they wander aimlessly out of boredom, cry out for company or comfort, or sit alone, disengaged from human and environmental interaction’ (Smith *et al.*, 2009).

Even if there are clearer motives with regard to wandering behavior, such as an explicit need to withdraw from the company of others, clients can be limited in

fulfilling these needs successfully, due to their cognitive or intellectual disabilities (including spatial disorientation), as was evidenced in our study by those clients getting lost and/or upset.

The “ideal user” which certain ST devices such as electronic bracelets presuppose, namely an independence seeking agent who knows where to go and make meaning of this, seems to be at odds with the needs of the actual user of ST, a vulnerable person with dementia or ID, who might benefit from increased freedom but also needs tailored support to actually be able to enjoy this freedom. What seems to underpin this presupposition is a deficient yet pervasive view of autonomy, which according to George Agich is deficient in its abstract view of “persons as independent, self-sufficient centers of decision making” instead of being sensitive to “the complex conditions that actually support the unique identity of those individuals needing long-term care.” (Agich, 2003).

Several health care professionals, ethicists and (patient) organizations have advocated refocusing the aim of ST towards a more person centered approach (Welsh *et al.*, 2003; Perry *et al.*, 2008; Alzheimer Europe, 2010), which in part finds its origins in the work of Tom Kitwood and is concerned with the maintenance and enhancement of personhood, by focusing on interpersonal relations instead of disease processes or impairment (Kitwood, 1997; Gilmour and Brannely, 2010). Staff intervention therefore need not come at the cost of autonomy, even though these are viewed as strictly dichotomous categories in long term care (Agich, 2003; Niemeijer *et al.*, 2011). For instance, in their study on access technology, Margot-Cattin and Nygard (2006) found that staff intervention was intertwined with autonomy, instead of being in opposition, stressing the importance of staff support of residents with dementia for all activities including wandering.

The autonomy of privacy

Differences in devices also mean differences in the experience of privacy: electronic bracelets enabled privacy by offering refuge from life in the unit, but cameras were experienced as privacy intrusive. In the literature on ST, a distinction is hardly ever made between enabling and intruding privacy- ST is generally viewed to be inherently intrusive (Robinson *et al.*, 2007; Hughes *et al.*, 2008; Niemeijer *et al.*, 2010), instead of as something which might also enable privacy, and consequently (personal) autonomy. This is underlined by legislation and several laws in European countries such as in Scotland and Austria, which designate(s) all ST as a form of restraint (Patrick, 2008; Heimafenthaltgesetz, 2011), by pointing to its inherent restrictive quality, namely monitoring.

Clients in long term residential care already have limited privacy, as one of the structural features of long term residential care is living together with other people (who you did not choose to live with). Hence, clients do not have many options with regard to creating ‘zones of intimacy’ for themselves other than their own private bedrooms (Hauge and Heggen, 2008). The ability to create more privacy could thus be perceived as one of the assets of ST, but the need for (and right to) privacy and consequently autonomy should continually be (re-) assessed per individual, so it becomes clear how the client experiences his freedom, rather than simply respecting his “right to be left alone”(Agich, 2003).

Consent and visibility

Certain ST devices, such as electronic bracelets which are visible on the body, can lead to (feelings of) stigmatization and result in refusals to wear them. By being able to explicitly say ‘no’ to (new) ST measures, it could be deduced that clients in our study were exercising their autonomy. However these were clients who were aware of the device and able to communicate (well), due to their mild(er) cognitive disabilities. At the same time, there were several clients who were not always aware that they were wearing an electronic bracelet, or that it was the bracelet which opened up doors for them. Although a client does not need to be aware of ST in order to make use of it, it does pose problems with regard to being able to consent to ST, which requires some form of volition, i.e. intentional choice. The fact that several ST applications are barely visible as they are designed to be unobtrusive (such as the motion sensors and audio surveillance which were embedded in the walls, but also the GPS tags sewn into the coats of clients) means that the less obtrusive devices are, the less aware clients are of their presence. This might ultimately result in higher (involuntary) compliance, as it difficult to grasp (the effects) of an ST measure which cannot be observed. Informed consent, “assent” (Black *et al.*, 2010) or (other) inclusionary approaches of supported decision-making (Peisah *et al.*, 2013) might not provide sufficient safeguards to invisible or unobtrusive technology.

Limitations

Accessing experiences of people with cognitive disabilities such as dementia or ID is complex and can be considered challenging (Nygard, 2006), thereby raising questions with regard to reliability of the data. We chose the method of participant observation where behavioral observation was central and used the additional interviews with staff and relevant others and information from the clients’ files to create a better understanding of these experiences. Although there is a risk in including other perspectives as it could lead to conflicting perspectives and

contradicting information (Margot-Cattin and Nygard, 2006), observation alone would probably not have elicited as much variety and richness of information, including comparisons with the situation before the implementation of ST.

Also, the limited size of the study population could raise questions with regard to the possible restricted (external) validity of its results. Data collection was limited to 2 residential care settings in the Netherlands and involved the observation of a relatively small number of examples of particular experiences. However due to the explorative nature of our study we focused on the extent of variation in which the observed situations occurred, and how exemplary these situations were, rather than statistical frequency (Glaser and Straus, 1967; Corbin and Strauss, 2008). Nevertheless, we are of the opinion that the experiences we describe are tenable in other care nursing homes and residential care facilities for people with ID, including those in other countries. This, however, is an issue that warrants further study.

CONCLUSION

Although coping involves managing a (stressful) situation, it does not necessarily mean mastery (Lyon, 2012). As clients cope with new spaces due to ST, they may manage or not manage at all, but any 'managing' can be (too) taxing and can also lead to resistance or refusal. It is this ambivalence which is characteristic for how clients might experience ST. This is in part owing to the variety in ST devices, with each device bringing its own connotations and experiences, but also lies in the devices' presupposition of an ideal user, which is at odds with the actual user, who is inherently vulnerable. What is more, unforeseen spin-off effects of ST measures sometimes take on more significance than the main purpose it was intended for, making it difficult to predict how clients will experience ST.

Thus ST in residential care should not be approached in a black and white manner, as being either positive or negative, but rather as something which can only contribute to the autonomy of clients, if it is set in a truly person-centered approach, tailored to the individual with his strengths and needs. For this reason continual and critical evaluation of and reflection on how each individual ST measure is experienced by clients is recommended, whereby clients are not simply left alone, but staff aim to support and give meaning to all ST related activities of people with dementia and ID.

REFERENCES

Agich, G. (2003). *Dependence and Autonomy in Old Age: An Ethical Framework for Long Term Care*. Cambridge: Cambridge University Press.

Alzheimer Europe. (2010). "The ethical issues linked to the use of assistive technology in dementia care" Alzheimer Europe Report, Luxembourg.

Bekkema, N, de Veer AJ, Hertogh, CM and Francke, AL. Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study. *Journal of Intellectual Disabilities Research* (epub ahead of print) Mar 19. 2013 doi: 10.1111/jir.12023

Black, B.S., Rabins, PV, Sugarman, J. and Karlawish, J.H. (2010). Seeking Assent and Dissent in Dementia Research. *American Journal of Geriatric Psychiatry*, 18: 77–85.

Boekhorst, S. Te, Depla, M.F.I.A., Francke, A.L., Twisk, J.W.R., Zwijsen, S.A. and Hertogh, C.M.P.M. (2013). Quality of life of nursing home residents with dementia subject to surveillance technology versus physical restraints: an explorative study. *International Journal of Geriatric Psychiatry* 28 (4), 356-363.

Corbin, J. M., & Strauss, A. L. (2008) (3rd Ed.). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage Publications.

DeWalt, KM and DeWalt, BR. (2010). *Participant Observation: A Guide for Fieldworkers*. (2nd ed.). Walnut Creek, CA: AltaMira Press.

Eltis, K. (2005). Predicating dignity on autonomy? The need for further inquiry into the ethics of tagging and tracking dementia patients with GPS technology. *Elder Law Journal*, 13, 387–411.

Gilbert, T. Involving people with learning disabilities in research: issues and possibilities. *Health and Social Care in the Community*, 2004; 12 (4): 298-308.

Gilmour, J and Brannelly, T. (2010). Representations of people with dementia. Subaltern, person, citizen. *Nursing Inquiry*, 17(3), 240-7.

Glaser, B.G. and Strauss, A.L. (1967). *The discovery of grounded theory*. Chicago: Aldine.

Hauge S and Heggen K. (2008). The nursing home as a home: a field study of residents' daily life in the common living rooms. *Journal of Clinical Nursing*, 17: 460–467.

Heimaufenthaltsgesetz. (2011). § 3. Freiheitsbeschränkung. Gesetzestext (Berücksichtigter Stand der Gesetzgebung: 1. Juli 2011 Österreich.

Hertogh, C.M.P.M. (2005). "Between autonomy and security: Ethical questions in the care of elderly persons with dementia in nursing homes." In G.M.M. Jones and B.M.L. Miesen (Eds.). *Care-giving in Dementia* (pp. 375–390). East Sussex: Brunner-Routledge.

Hoare, KJ, Buetow, S, Mills, J and Francis, K. (2012) Using an emic and etic ethnographic technique in a grounded theory study of information use by practice nurses in New Zealand. *Journal of Residential Nursing*, (Epub ahead of print) may 25: doi: 10.1177/1744987111434190.

Hughes, J.C., Newby, J., Louw, S. J., Campbell, G., and Hutton, J. (2008). Ethical issues and tagging in dementia: a survey. *Journal of Ethics in Mental Health*, 3, 1-6.

Kitwood, T. (1997). *Dementia Reconsidered: The Person Comes First*. Buckingham, U.K.: Open University Press.

Lincoln, Y, & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.

Lyon, B. (2010). Stress, Coping, and Health. A Conceptual Overview. In: Rice, V.H. (ed). *Handbook of Stress, Coping, and Health Implications for Nursing Research, Theory, and Practice* (2nd Ed) Thousand Oaks, CA: Sage Publications, pp. 2-20.

Margot-Cattin, I. and Nygard, L. (2006). Access technology and dementia care: Influences on residents' everyday lives in a secure unit. *Scandinavian Journal of Occupational Therapy* 13: 113-124.

Niemeijer, A.R., Frederiks, B.J.M., Riphagen, I.I., Legemaate, J., Eefsting, J.A. and Hertogh, C.M.P.M. (2010). Ethical and practical concerns of surveillance technologies in residential care for people with dementia or intellectual disabilities: an overview of the literature. *International Psychogeriatrics*, 4: 1–14.

Niemeijer, A.R., Frederiks, B.J.M., Depla, M.F.I.A., Legemaate, J., Eefsting, J.A. and Hertogh, C.M.P.M. (2011). The ideal application of surveillance technology in residential care for people with dementia. *Journal of Medical Ethics*; 37(5): 303-10.

Nygaard, L. How can we get access to the experiences of people with dementia? Suggestions and reflections. *Scandinavian Journal of Occupational Therapy*, 2006; 13: 101-112.

Patrick, H. (2008). *Autonomy, benefit and protection. How human rights can protect people with mental conditions or learning disabilities from unlanful deprivation of liberty*. Mental Welfare Commission for Scotland. Edinburgh, pp. 1–52.

Peisah C, Sorinmade OA, Mitchell L and Hertogh CMPM. (2013). Decisional capacity: toward an inclusionary approach. *International Psychogeriatrics*, 7: 1-9.

Perry, J., Beyer, S. and Holm, S. (2008). Assistive technology, telecare and people with intellectual disabilities: ethical considerations. *Journal of Medical Ethics*, 35, 81-86.

Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J.C., Brittain, K. and Bond, J. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health Risk and Society*, 9, 389-406.

Smith, M, Kolanowski, A, Buettner, LL and Buckwalter, KC. Beyond bingo: meaningful activities for persons with dementia in nursing homes. *Annals of Long Term Care*, 2009; 17, 7: 22-30.

Welsh, S, Hassiotis, A, O'Mahoney, G and Deahl, M. (2003). Big brother is watching you: the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging and Mental Health*, 7: 372–375.

Wigg, J. (2010). Liberating the wanderers: using technology to unlock doors for those living with dementia. *Sociology of Health and Illness*, 32, 7, 288-303.

Zwijssen, S.A., Depla, M.F.I.A., Niemeijer, A.R., Francke, A.L. and Hertogh, C.M.P.M. (2012). Surveillance technology: an alternative to physical restraints? A qualitative study among professionals working in nursing homes for people with dementia. *International Journal of Nursing Studies*, 49 (2), 212-219.